



Being Misunderstood

Scotland Report

Experiences of the
Pathological Demand Avoidance Profile
of ASD

November 2018



Introduction

There is a group of autistic people for whom the conventional highly structured approaches are not only unhelpful but can lead to increased and debilitating stress. Instead, collaborative approaches to learning and daily living tasks are significantly more effective.

This need for a different approach makes it essential for this group to be identified, even though research into causation and relationship to other conditions is in its infancy.

The PDA Society conducted an online survey for two weeks in March 2018 through their website and social media. 1,445 parents, professionals, adults with PDA and their partners or family members contributed. The results are available online via the PDA Society in a report entitled 'Being Misunderstood'.

This regional report details some of the experiences described by parents living in Scotland. The comments powerfully demonstrate the impact that the lack of understanding can have.

Overall, the results demonstrated that in practice, a constellation of traits is being identified by some who diagnose ASD, though it is less common in Scotland. When identified it is most often done through use of terminology which reflects the idea of a 'Pathological Demand Avoidance profile of ASD'.

However, parents report that a lack of understanding (and sometimes acceptance of the profile) is the biggest barrier to getting support. Adults and children are regularly being misunderstood, with services consequently failing in their duty to be needs-based and outcomes-focused.

For outcomes to improve, professionals need to know that they can speak openly about this group using unambiguous terminology and, most importantly, promote appropriate strategies.

For this to happen, local leaders of adult and children's services which support autistic people must frame the way in which this complex autism can be managed. This is likely to be best achieved through publication of a 'position statement' for professionals and service users, along with resources for staff development.

National Key Findings:

70% of 969 young people were not able to tolerate their school environment or were home educated.

71% of 79 adults and 70% of 1194 parents reported that they had found a lack of acceptance or understanding of PDA a barrier to getting relevant support

67% of 675 parents reported that they were dissatisfied with the help received from their Child and Adolescent Mental Health Service (CAMHS); only 20 individuals reported that a CBT-type approach had helped.

49% of 768 young people with diagnoses had been given one that included PDA or a demand avoidant profile, or used similar terminology.



Survey of Parents in Scotland

About the respondents

Demographic questions indicated that respondents were fairly representative of the population as a whole in terms of income and geography, but not of ethnicity, with just a handful of individuals from minority ethnicities involved.

The sample size was significant with 1,445 participants, and so this represents the largest survey on this topic conducted to date. The largest group were parents of children and young people who they had identified as or suspect may have a PDA profile of ASD. These made up 1,194 of the respondents, including 86 families from Scotland.

1. Diagnoses

Answer Options	Scotland	National
Yes, given what I feel is a correct diagnosis	26%	32%
Yes, but I feel it is incomplete	21%	22%
Yes, but not one I agree with	5%	3%
Still waiting for a formal diagnosis	20%	14%
Not requested / been offered a formal diagnosis	5%	7%
Other... (comments below)	24%	23%

- Requested a diagnosis for PDA at CAMHS but told it's not recognised. As she's adopted they assume she has attachment disorder, which she has traits of as well, but she fits the PDA profile 100%.*
- My son has had an initial SLT assessment and has now been referred to the Community Paediatrician. CAMHS Motherwell have rejected a referral from the GP on two occasions. He is currently attending a Child Psychotherapist that we have seemed out privately as no other support has been offered by the NHS.*
- Awaiting paediatrician appointment for further assessments.*
- No, once you reach 16 less support, everyone wipes their hands of you, doctors won't listen to your parents, the only ones willing to help and speak out for you and who knows you better than any one! adult services! no chance of any diagnosis even though you struggled to attend high school and came close to being put into a residential care home. All forgot about and left to get on with your struggles with no qualifications, communication problems, isolation, no life.*
- They were careful in diagnosing autism to mention that he seemed to be fine when he was with me or them and relaxed but that they strongly despite that presentation that he was PDA, and they put a note POST headline diagnosis saying that these strategies may be more appropriate. This helped. They said if it was not treated as such we'd be back.*
- Currently seeing CAMHS for anxiety*
- Requested CAMHS / ed psych referral for non-attendance at school and extreme anxiety. was turned down.*
- Not recognised in most of Scotland.*



- We were told he has PDA although it is not a recognised diagnosis in North Ayrshire but my friend's son has PDA and he has been officially diagnosed but he lives in East Ayrshire.*
- Been refused out of area referral. Scottish Borders.*
- they refuse to acknowledge PDA in Aberdeenshire so won't diagnose.*
- He is diagnosed with Asperger's, CAMHS say PDA is not recognised in Scotland although one mental health therapist acknowledged he has traits*
- diagnosed with ASD. Professionals in our area do not recognise PDA as a profile, although I have been able to discuss strategies that work with them. They said strategies are ok, they just don't diagnose it. However, more recently, daughter's Paediatrician mentioned in one of her letters that daughter is controlling and demand avoidant at home, where previously she said they don't recognise the profile. So, I think awareness is increasing.*
- Was giving informal diagnosis at my request of it being informal as ASD with PDA*
- Do not diagnose here. I mention it and his placement school have written PDA strategies in his plan but at no point do they call it or mention PDA and talk about ASD.*
- Yes took 3 yrs*
- Refused an assessment by neurodevelopmental assessment team, handed back to CAMHS for treatment of her anxiety.*
- Was diagnosed with autism 16 years ago, so no awareness of PDA then*
- Autism diagnosis but not PDA, am going to make enquires to get this added to medical records soon*
- Been refused an out of area referral by NHS Borders.*

2. Challenges faced

These young people face significant challenges, with all parents identifying a range of issues including school refusal and eating problems. The top 5 concerns were in line with the national picture:

Answer Options	Scotland	National
Need to feel in control	91%	96%
Challenging behaviour	86%	89%
Sensory issues	85%	81%
Difficulty with daily routines	84%	78%
Challenging behaviour	86%	89%
Severe anxiety	81%	81%

3. Does your child struggle to get into school?

These figures include children who are home-schooled

Answer Options	Scotland	National
Yes, all the time	39%	41%
Regularly	28%	25%
Sometimes	14%	15%
Occasionally	9%	10%
Never	9%	8%

4. Involvement of Local Services

84% of families had involvement from local services, often multiple services, over the past 2 years. This included almost two-thirds of respondents (65%) who had attended CAMHS services.

Respondents were asked whether the help they had from local services had enabled them to understand their child better and/or enabled them to manage any difficulties better. The responses demonstrate the complete ineffectiveness of services.

Answer Options	Scotland	National
Completely	1%	1%
Very	5%	4%
Moderately	7%	13%
Slightly	26%	24%
Not at all	48%	45%
Not applicable	13%	12%

Of those who had visited CAMHS, the satisfaction levels were mostly poor.

Answer Options	Scotland	National
Very satisfied	6%	3%
Fairly satisfied	15%	14%
Neither satisfied nor dissatisfied	16%	15%
Fairly dissatisfied	21%	19%
Very dissatisfied	42%	48%

Some explained their experiences of local services

- We have done our own research.*
- I have managed to secure a worker from a social work budget but no specific input from SW or CAMHS on PDA beyond what I've been able to fight for. They only tolerate the demand avoidance label as they have no other avenues to explore, in my opinion. In two local authorities, and in three different (1 mainstream, 2 specialist) school settings no practitioner has successfully managed to engage my daughter. CAMHS have persisted but in both LA did want to discharge her due to her 'non engagement' I had to insist that it was their responsibility to reach her. My daughter will see the CAMHS worker, but again, this is intermittent. My only hope is that in time my daughter will again contemplate talking therapy and/or meds, and meantime myself and support worker provide companionship and support.*
- They have consistently said they have nothing to teach me; I'm a voracious reader and researcher very experienced with kids including ASC; and they have been supportive in helping me communicate with the school. The school is the only place I've had real bother. Just the*

other day after three and a half years and a diagnosis the DHT suggested a solution to the taxi company being busy at rush hour meaning we are ON TIME INSTEAD OF EARLY was to cycle with my demand avoidant school refusing child through urban traffic at rush hour down a main road that is a death trap. It takes him 45 minutes just to put on a shoe. I despair. How can you educate someone like that?

- Having the back-up of CAMHS has been helpful to me as a back-up, it has provided me someone to talk to and has offered some helpful general techniques that sometimes work (sometimes don't!). Not sure it has been helpful for my daughter who has only attended two sessions. I have found my occasional meetings with CAMHS have been useful in reminding me that I am dealing with a 'condition' which helps diffuse the stress that builds up - as opposed to the up-hill struggle of day-to-day where it can just all feel like negotiation and unreasonable behaviour.*
- Tried and failed over at least 6 years to get help and the situation has gotten gradually worse now daughter has just turned 16 and her school are trying to force us to take her off the school roll. She needs help to attend school not to be forced out.*
- As the 'help' I have received has been totally inappropriate and lacking in any form of support, it has made me find out as much as possible myself. My two children have been home schooled now for two years and in that time, there has been no support whatsoever education wise. The lack of support has transformed our house in that I have to, and do, deal with things as effectively as I can on a daily basis. But (and this is a big but) I am incredibly upset, distressed and angry that my children seem to have just fallen through the system and are not even acknowledged.*
- At times the help has been counterproductive due to refusal to recognise PDA as a formal diagnosis and refine any help. Now have a second child psychiatrist who is more helpful.*
- Receiving the diagnosis confirmed to me what I had already known for many years, but almost my entire understanding came from my own research.*
- Still without support apart from a few letters from Borders Carers. GP very supportive.*
- CAMHS are helpful however for his ADHD. Occupational therapist was useful to understand sensory issues. Social work it's a battle to get them to help. However now have some respite in place.*
- The voluntary sector support has been the best and 2 specific CAMHS people out of many.*
- I run my own support group for parents as there is nothing for us to support us or our children.*
- Everything I have learnt is through self-research and other charities*
- No help from any services*
- No I've done it all myself understand my child because I've put the hours of research in.*
- I have educated myself online, through forums articles and attending workshops including one run by PDA society. I find educational psych and schools view of ASD to be the textbook example and it does not apply to my son.*
- Not had any help*
- We have had to find out most of our information by ourselves through groups like the PDA Society.*

- 19 We are all being refused any support.
- 20 When it was first suggested my daughter might be autistic I completely disagreed because I couldn't see her communication difficulties or social inappropriateness. I learnt more about it and finally came across PDA which fitted her symptoms so much better than Aspergers. This helped me change the way I treated her and now my expectations are far lower because I realise she simply isn't capable of acting the way I wanted her to in the past.
- 21 The only help we have had is attending the Early Bird Plus Course run by Speech & Language Therapists through the NHS. A lot of it, we already knew though. There were a couple of 'light bulb moments' throughout the course where we have changed our tactics to manage certain situations. What was more useful to us was the discussions between the parents who attended and discussing what has worked for them with difficult behaviour.
- 22 I have read about PDA for myself
- 23 Support through courses and support groups, sharing experiences and strategies with other parents and professionals.
- 24 Absolutely useless, I educated myself by reading many, many late nights online, including books and talking to other parents via group chats
- 25 I have taught Borders Carers the issues. I have also worked with my GP. I have worked with Tutors at Edinburgh College.
- 26 NAS training was helpful in understanding autism. Apart from that there is no help.
- 27 Everything has been down to us (parents) pushing and learning about PDA ourselves to enable us to provide the correct support for our daughter.
- 28 We are very lucky to have ARCH Autism Centre in South Lanarkshire, who accept PDA. The Centre has regular small PDA workshops from the Diagnostic Team. They also piloted the NAS Healthy Minds Programme which is centred around identifying your child's traits and finding appropriate strategies to help. There were 4 families whose child has PDA attending and a number of the PDA strategies helped all 4 families immensely.

5. The Challenges of having a PDA child

82 people described the challenges they faced. A few examples are included here.

1. **Want people to stop blaming me and understand about PDA and the impact it has on my family**
2. Getting her to school. No help from school only threats of prison/ fines or referral to children's panel.
3. That nobody has done anything to help. It has never been mentioned to me at all. We have seen social workers, Camhs, doctors and hospital nurses who have all been unhelpful, one even diagnosed my son as just naughty.
4. Getting appropriate support, child protection procedures resulting in child being removed from home

5. Getting any support , fighting the system 24/7 . Lack of understanding and so few willing to learn. The entire system is corrupt and covers up the truth.
6. Always "switched on". Never feel able to relax at home or in public as always on the lookout for triggers.
7. Learning how to treat her differently. With respect, explain everything. Taking away anything that may cause fear and anxiety.
8. We have another child with ASD - Asperger's Type and managing their opposing needs. Both parents having chronic insomnia due to stress. Feeling quite isolated and having to do things differently.
9. Other people including professionals having no understanding what so ever and thinking my child is just badly behaved or that I'm not a strict enough parent.
10. Initially realising what works and what doesn't and having some epic battles. Now it is getting the school to accept these strategies and apply them consistently. Placement school are amazing and work tirelessly with him to achieve learning. Mainstream can't or don't have time resources to get him to do anything unless he decides to. He is never violent towards me or children or other adults, but I will be called by or to the school to be informed of regular hitting/kicking of authority figures at school.

Overarching all of this is having to make my son go to somewhere he hates and has low self-esteem from interactions with school. I wish it could be easier for him and the staff.
11. The daily battles to keep her safe, secure and with some sort of life worth living. Also the daily battle to maintain a functioning level of mental health and keep some sort of life both inside and outside the home.
12. Caring for my daughter has taken over my life and makes me wish I didn't have children. It makes me so anxious and exhausted and angry which makes me very difficult to live with. It has changed who I am and turned me into someone I dont want to be.
13. always having to prove you arent lying or munchausens, you know instantly when they are insinuating you are.
14. Dealing with discrimination, dealing with ignorance and non acceptance of a disability. Our child's actual disability is easy to understand but not to explain to people who didn't want to understand
15. We've had to fight for everything, we had to involve a solicitor while she was at nursery for her to get the proper support and that has just continued, we legally fought for her school placement and fought to get her a Co-Ordinated Support Plan (Scotland's similar version of EHCP), we've been met with barriers from everybody involved with our child, Education is such a challenge as they fail to see bigger picture and won't accept her type of profile because it isn't recognised.

Final comments

At the end of the survey, respondents were asked if they had anything to add. These are the comments provided.

1. *Trying to bring up a child with PDA has ruined our relationship as a married couple, caused mental health problems and destroyed our friendships with others. As our daughter is so good at manipulating and performing, nobody realises the true price of trying to keep things together. We have gone from being two strong, bubbly, sociable and successful people to isolated, stressed nervous wrecks. Our situation is heading towards breakdown.*
2. *Huge problem with CAMHS failing to get involved if there's an ASD diagnosis, which allows them to manage waitlists. They refuse to accept clear mental health issues and instead, say its part and parcel of ASD. Our ASD children are being failed, us families are left to cope alone. We need a CAMHS service dedicated to ASD and ready to support our children.*
3. *Having a child with PDA is the most soul destroying and heart wrenching life ever. The understanding of PDA is not widely talked about. But when things are going well, it's worth all the torment and anguish, just to enjoy life.*
4. *Hard to say as my son is very difficult at school from what I see. Also, if conference was on near us and after work hours or Wednesdays I'd like to go thanks*
5. *I find what's most challenging is my son is very intelligent, does really well with most school work but has massive meltdown after school from holding it in all day, school don't seem to see an issue as his work is fine. I believe if he had help and support from education, imagine how much more he would be capable of doing if his anxiety and stress was reduced.*
6. *I knew from a very young age my daughter was different and for fourteen years myself and my family has been through hell all through primary the schools answer was to restrain my daughter or send her home at the age of ten they called the police and she was hand-cuffed as a means of restraining her this happened many times. Also no one believe me and our local calms said it was attachment disorder which I knew was wrong. In June, I went for a private diagnosis and was told she had PDA and various other disabilities. Again, I asked for help through my local GP and was told yet again she has nothing wrong with her and if I need help go to quarries. My health is now suffering and I am in the proses of suing them. I would love to go public so the world knows what's going on and how this is destroying families.*
7. *My child has always had problems with school which started with speech therapy at nursery. Pushed from p2 to get her tested for dyslexia but told as she only regularly hit 7 /10 markers they wouldn't fund it but recommended we get private testing. This would have cost over £500 so we couldn't do it. Eventually diagnosed with mearirlen syndrome in year 3 of secondary school after suggestion from SEN. Again, no funding for dyslexia tests. Still doesn't get what she needs for existing diagnosis never mind fighting to get further diagnose. Constant brick wall and I'm sure it's all funding based. They just don't want to spend the money on her. I feel the system has continually failed my child and I am worn out pushing and fighting for what she needs.*

My daughter wants to go to university and eventually become an architect but school is trying to push her out without any qualifications as she is 16 now because of her attendance % at school.

8. *The total lack of understanding throughout the system of PDA and Autism Spectrum. PDA is totally misdiagnosed in my opinion. Try 1 in 5 for figures of ASD not 1 in 100*
9. *I have 3 children with an ASD diagnosis. 2 of them have a PDA profile. It's a real struggle to manage 3 very different set of needs and I receive very little help and support.*
10. *Feel like I'm constantly fighting with all agencies to try and get my child help and support... He has a coordinated support plan and additional learning plan which I Again had to fight for... I just wish I never had to fight for help all the time*
11. *Biggest issue is treatment options. Speech and Language say the best course of treatment is psychological services but CAMHS do not treat ASD without a co-morbid condition. Many parents being left with no support at all.*
12. *I think in North Lanarkshire things are starting to change for children with PDA but very slowly. There are 2% of children living in North Lanarkshire with PDA.*
13. *My daughter received no formal secondary education and was completely let down by the education system.*

In adult mental health services in our area there is no mental health professional who is trained in autism, let alone PDA.

Although CAMHS are stretched and could have done more if they had the resources and experience my daughter wouldn't be alive if it wasn't for their support.
14. *I have experienced violence by my son to the extent where I had to ring the police on two occasions as I feared for my life. He is 16 now and over the violence, the hardest years by far have been from the ages of 7-14, they were truly awful. Severe lack of help from social work dept. and young people's department don't want to help as my son is not on medication and they would not even consider PDA.*
15. *Life is pretty hopeless. Why do I have to fight with every service just to even be heard and then there's little anyone can offer.*
16. *Horrendous experiences of very low moods and exhaustion of daily battles. A struggle to get up and face a new day. Feeling hopelessness. Disappointed I can't work to help my family. Isolating and primary was awful as head was a bully. There is more lows than I have ever experienced.*
17. *Took 7 1/2 years for a diagnosis in the meantime our family suffered and no early effective intervention given. We were given attachment. He has been out of school since P2 with 1 hr a week mainstream he currently now has 12hrs a week but that was due to getting an education solicitor involved. He is now in P6 and can hardly read or write. He is an extremely able and capable boy who within the right environment his*

potential could be huge.

Disability Social Work have been useless and bully me into doing consequences which they wouldn't listen to me that they don't work. They have threatened me with residential and currently want him to go into foster care for respite!!

18. *Not having official recognition of PDA profile in this area is causing me great anxiety and has added hugely to my stress. we are struggling but have not put our family forward for a SW assessment, due to hearing the negative experiences of other families. We have contacted the school for a "meeting around the child" to find out about supports for the family.*
19. *After a very shaky start with mainstream who seemed to believe all kids were bad before they got a diagnosis they are now attempting to work with me and take advice. It is very hard for them to cope with all the many needs of the class and my son requires a huge amount of focus and effort. Even at spec school he is one on one for most of the time. He is v respectful of adults unless they are authority figures mainly at school. Whilst not a violent boy he tends to solve problems at school with his fists or will answer with a solution that he would kick or hit. He does not harm peers or parents or peer's parents. He is respectful and polite, yet thinks he should beat up police if they arrested me for example.*
20. *I am so exhausted by the lack of knowledge and belief about this condition from professionals. The damage this does to the children is huge. Also, education in this country does not accommodate our kids.*
21. *My child's difficulties make life hard, but the lack of coordinated support and understanding makes things far harder. My son has come a long way, but due to professionals continually changing jobs every time we get someone new involved they change things based on their immediate observations and so set him back.*
22. *Once my daughter was diagnosed with Autism, I naively thought all this support would roll in. Unfortunately, this didn't happen. Attending 6-monthly Paediatric appointments are a complete waste of time - they are only for the NHS to tick a box to keep us in the system. I had to do all my own research on Autism and when I discovered PDA, everything fell in to place and I had a better understanding of some of my daughter's behaviours. I provided her school with a lot of PDA information to give them insight too. We just manage her behaviour on a day to day basis as she can be different every day and what will work one day won't work the next. Support for Autism never mind PDA is very very poor in my experience. There are a lot of families out there doing the very best they can with little or no support. In my opinion, this is only going to create mental health issues in the parents as it is so draining and challenging caring for a child with Autism on a daily basis.*
23. *CAMHS never carried out any meaningful assessments and refused to acknowledge any condition/diagnosis. They promised an assessment to see if my daughter would be suitable for psychological therapy on the condition that we attended a Triple P course. After attending and upon assessing her, they claimed it was an 'anger issue' which they don't work with, then discharged us.*
24. *there is a massive lack of PDA support in Scotland, even moving here with an NHS England diagnosis isn't worth the paper it's written on. My child needed CAHMS for*

PTSD caused by mishandling and abuse from school staff physically, mentally and emotionally due to the ignorance of PDA and its very specific strategies, because they don't endorse it here. We have been through hell here, police investigations etc., staff are never held accountable even when our kids have actual bruising etc. and tell them exactly what happened and who did it, it's the same all over Scotland and why PE1548 was petitioned to Hollyrood, our case was 1 of the supporting cases for the petition alongside 100s of others against the practice of seclusion and restraint!

25. *The acknowledgement from everyone having contact with these children that this is a condition that requires support.*
26. *My son's father was abusive & has not lived with us for 11 years. However, professionals who don't understand autism & PDA have supported him in pursuing a court order for weekly access with my son. The court stopped the access for my daughters because they told a psychologist of the abuse. My son was not able to be interviewed because of his autism so his access continued- this was extremely frightening for my son. Now as a young adult my son once again faces the trauma of the court forcing him to see his abusive father- because my son is autistic his rights are being ignored.*
27. *Due to the lack of understanding outside our own family we worry a lot about what the future holds for a child with PDA. People assume when you say a child as autism that this will come with major behaviour issues, our child doesn't have this regularly so getting him into clubs/groups where he is supported is also incredibly hard so we have to pay for private lessons or travel out with our own area to get services/activities that are right for him. It is a struggle to constantly search, hold down employment and maintain any kind of quality of life.*
28. *Had a difficult experience & still am even though we have a diagnosis. The key for us was her assessment with an experienced clinician who knew what they were looking for and could see beyond surface ability. Very negative opinions regarding PDA among professionals and I was even asked if I was sure she didn't have ODD even though her diagnosis report was sitting in front of her. I do believe without our solicitor and his involvement we wouldn't be sitting this far along in our fight, we've met to be at tribunals twice in the past 6 months but LA have stepped down. In effect we've paid for her to have her school placement etc.*
29. *The corruption within the system, LA, Teaching, NHS, Ministers to cover up the truth beggars belief. Try 1 in 5 on the Spectrum by my experience. That a teacher in Scotland can refuse ASD training beggars belief. They have a duty to protect a child's mental health and make them feel nurtured and well respected. What the Scottish Government don't want to admit is even if CAMHS don't recognise PDA the teachers have breached Education Laws by not using PDA Strategies. There is no system to check who is upholding these laws. If there was as much effort to cover up the truth as there was in finding out a diagnosis then my children should have been diagnosed at five and three.*
30. *There is very little understanding of autism and PDA within education and health professionals. This must change. The strategies used for a PDA child is often seen as weak parenting and therefore parenting must be the problem despite actually having a diagnosis. There is no acceptance or help. The system is broken, under-funded and under resourced. The pressure put in families is immense.*



31. *The PDA society have been a life saver in my eyes. To finally have people that know what they're talking about and believe us as parents. It's great to get the support and identification with others. We attended the PDA training in Glasgow last year and it was great. My husband came along and it really helped him to understand our daughter better. Thank you.*
32. *I'm in Aberdeen. CAMHS say PDA is not a diagnosis and don't recognise it. However, another professional in the same CAMHS department have diagnosed another child with PDA. I knew it was a postcode lottery to get diagnosis, but in our local authority there is not even agreement between professionals within the same department regarding status of PDA diagnosis!*
33. *I think it's important to work alongside professionals. Discuss the profile of PDA, educate others around you. Change mindsets. If it can happen in our area it can happen in other areas.*
34. *Trying to bring up a child with PDA has ruined our relationship as a married couple, caused mental health problems and destroyed our friendships with others. As our daughter is so good at manipulating and performing, nobody realises the true price of trying to keep things together. We have gone from being two strong, bubbly, sociable and successful people to isolated, stressed nervous wrecks. Our situation is heading towards breakdown.*



Conclusions

This report illustrates the experiences of those with a PDA profile of ASD who are living in Scotland.

Reading about these experiences should be a wake-up call to those supporting and providing services to the autistic community. Individuals who may be described as having a PDA profile are being neglected and even discriminated against because of a lack of acceptance and understanding of their needs, leading to a failure to put in place reasonable adjustments.

At the same time, the results demonstrate that explanatory terminology is being very widely used in some parts of the country. Where this happens, understanding of strategies can follow. Even then, much more support is needed for local services to become sufficiently familiar with useful interventions.

It is unacceptable that 70% of young people in families surveyed are either at home or struggling to access school environments, and because their needs are being misunderstood, many are missing out on education. Local services, including children and adolescent mental health services were found to be completely ineffectual, which compounds problems and leads to parents finding themselves unable to cope.

It is in the interest of everyone that professionals are empowered to see the individual and focus on improving outcomes. The national report provides a detailed list of recommendations for action, summarised here:

Local Authorities and Commissioners across the country must urgently communicate their position on the PDA profile of ASD to service providers and their clients, to clear up the confusion over assessments and service availability that currently exists.

Government and autism leaders must consider why so many people are being failed and press Local Authorities and Commissioners to create the conditions so that needs are assessed fully and in a collaborative manner, so services can be truly outcomes-focussed.

Education services and schools must increase their awareness of the needs of individuals with a PDA profile of ASD, and how to make reasonable accommodations.

Autism education and training providers should ensure that differing responses of individuals across the autism spectrum, including those with a PDA profile, should be included in autism courses and literature.

Providers of mental health and autism services need to ensure that their staff are equipped to identify and work with those with a PDA profile, whatever terminology they choose to use.

Professionals should ask themselves what more they can do to develop their own understanding and that of others, and challenge themselves to be open to the explanations of individuals and parents.

About the PDA Society

The PDA Society was set up to provide information and advice to parents and is currently in touch with over 14,500 people through its membership, forum and social media. Its volunteers directly advise up to 2,000 people each year and training courses are available for parents and professionals. The Society's website includes a range of resources including webinars, links to books and academic papers.

www.pdasociety.org.uk

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